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ORIGINAL ARTICLE ÖZGÜN ARAŞTIRMA

The Assessment of Factors Related to Family Life in Children with Cerebral Palsy

Serebral Palsili Çocukların Aile Yaşantısı ile İlişkili Faktörlerin İncelenmesi

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Abstract

Introduction: Many permanent problems can be seen together in children with cerebral palsy (CP). Therefore they need lifelong care and there are many factors that affect the family life of children with CP. The aim of this study was to investigate the relationship between factors such as the level of independence in daily living activities in children with CP, motor function levels, type of CP, and emotional state, cooperative activities, self-time, and family adjustment in the family.

Materials and Methods: Two hundred and sixteen children with CP in an age range of 4-18 years were included in the study. The relationship between the WeeFIM, motor function levels, the number of siblings, and the parental impact-emotional, parental impact-time, family activities, and family cohesion domains of the CHQ-PF50 were examined. The effects of the type of CP on family life were investigated.

Results: A positive weak correlation was observed between the WeeFIM, the number of siblings and CHQ-PF50 values ($p<0.05$). A negative weak correlation was observed between the motor function levels and parental impact-time ($p<0.05$).

Conclusion: It was concluded that family life was positively affected with the increase in the independence levels of the children with CP in daily living activities. As the motor function levels of children with CP deteriorated, families were negatively affected in terms of time management. It was observed that having siblings had positive contributions to family life for children with CP.

Öz

Giriş: Serebral palsili (SP) çocuklarda pek çok kalıcı problem bir arada görülebilmektedir. Bu nedenle yaşam boyu bakıma ihtiyaç duyarlar ve SP'li çocukların aile yaşamlarını etkileyen birçok faktör bulunmaktadır. Bu çalışmanın amacı, SP'li çocukların günlük yaşam aktivitelerinde bağımsızlık düzeyi, motor fonksiyon seviyeleri, SP tipi ile aile içindeki duygusal durum, birlikte yapılan aktiviteler, kendine zaman ayırma ve aile uyumu arasındaki ilişkiyi incelemektir.

Gereç ve Yöntem: Çalışmaya 4-18 yaş arasında SP tanısı almış 216 çocuk dahil edildi. Çocukların WeeFIM değerleri, motor fonksiyon seviyeleri, kardeş sayısı ile CHQ-PF50'nin ebeveynler üzerindeki emosyonel etki, ebeveyn üzerindeki zaman etkisi, aile aktiviteleri ve aile uyumu bölümleri arasındaki ilişki incelendi. SP tipinin aile yaşamına etkileri araştırıldı.

Bulgular: WeeFIM ve kardeş sayısı ile CHQ-PF50 değerleri arasında pozitif yönde ve zayıf bir korelasyon gözlendi ($p<0,05$). Motor fonksiyon seviyeleri ile ebeveyn üzerindeki zaman etkisi arasında negatif yönde ve zayıf bir korelasyon olduğu belirlendi ($p<0,05$).

Keywords
Cerebral palsy, activities of daily living, family, child

Anahtar kelimeler
Serebral palsi, günlük yaşam aktiviteleri, aile, çocuk

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Sonuç: SP'li çocukların günlük yaşam aktivitelerinde bağımsızlık düzeylerinin artmasıyla aile yaşamının olumlu yönde etkilendiği sonucuna varıldı. SP'li çocukların motor fonksiyon seviyeleri kötüleştikçe ailelerin zaman yönetimi konusunda olumsuz yönde etkilendiği belirlendi. SP'li bireylerin kardeş sahibi olmalarının da aile yaşantısına pozitif katkıları olduğu gözlendi.

Introduction

Cerebral palsy (CP) is a clinical condition affecting many systems in a developing brain as a result of permanent, but non-progressive, damage. As a result of the involvement of the central nervous system, many physical, mental, emotional, and cognitive problems may occur concurrently (1,2). Because these problems are persistent and progressive, children with CP need lifelong care and treatment. A transdisciplinary approach is very important in the treatment of children with CP and the family is at the center of the rehabilitation process. The existence of a disabled person in the family lay additional responsibilities on all other family members. In addition, families of these children may encounter situations such as not having enough time for their other children and not being able to assume their roles in the society (3).

According to the International Classification of Functioning, Disability and Health-Child and Youth Version, children's essential context is family. Therefore, there is a strong relationship between the well-being of children with neurodisabilities and the well-being of families (4).

The level of functional independence of individuals with CP varies. Age, the affected area in the central nervous system, the degree of involvement, the gains achieved by the individual during the treatment process, and secondary and tertiary problems caused by CP cause the functional independence level of each individual to be different from each other (5,6).

In the event that the severity of dysfunctions increases, many individuals with CP need help from their parents in many daily living activities, such as eating, self-care, dressing, mobility, and bathing. The evaluation of the quality of life of the parents who provide care for a child with CP who has not gained independence in meeting his/her daily needs is an important issue in social life. The impact of the responsibilities and emotions of the parents (towards themselves, each other, and other family members) on the family life should not be overlooked. Parents who have difficulties in coping with difficult and complex problems in time management and individuals with CP who have disability in self-care should be supported in many areas (7).

In the literature, it has been shown that the quality of life of mothers of children with CP decreased compared to the mothers of typical healthy children (8,9). In addition, it has been reported that stress and depression levels were increased in families with disabled individuals (10-12). It was reported in a study that siblings of children with CP helped their families during the intervention process and were facilitating role models for their siblings (13). The relationships of children with CP with their healthy siblings have been frequently examined in studies; however, there is no study in the literature examining the relationship between the presence of siblings and family life in families of children with CP. It was hypothesized that factors such as the levels of independence of the children with CP in daily living activities, GMFCS, the type of CP, and the number of siblings would affect the family life. The aim of this study was to investigate the relationship between the levels of independence of children with CP in daily living activities and motor function levels, the type of cerebral palsy, the number of siblings, the emotional state in the family, the activities performed together, self-time, and family adjustment.

Materials and Methods

Participants

Two hundred and sixteen children with CP were included in the study. This study complied with the ethical standards of the Declaration of Helsinki, and all subjects and parents received explanations regarding the purpose and procedure of the study before voluntarily agreeing to take part. The ethics committee permission was obtained from the Ethics Committee of Gazi University on 14.05.2019 (approval number: #91610558-604.01.02). A written informed consent was obtained from the parents or legal guardians of all participants.

Inclusion criteria for our study were: being in an age range of 4-18 years, being diagnosed with CP as a result of appropriate evaluation methods by a pediatric neurologist, and to volunteer to participate in the study. All of the children participating in the study were diagnosed with the disease properly because they all had a disability health report from a well-equipped hospital, and they were attending a special education and rehabilitation center based on this report. Children who had undergone surgery or any invasive intervention within the previous 6 months were not included in the study. After demographic information of the children, such as age and gender, were recorded, their parents' age and the number of siblings were inquired. The type of involvement (Unilateral, Bilateral, Dyskinetic, and Ataxic) of the children with CP was also recorded.

Measures

Gross Motor Function Classification System

The Gross Motor Function Classification System (GMFCS) was used to classify the motor levels of the individuals. The GMFCS is a standard classification system consisting of five levels. Level 1 shows the slightest impact and level 5 shows the most severe impact (14).

WeeFIM

The WeeFIM, known as the Functional Independence Measure, was used to determine the level of independence of the individuals with CP in daily life. The WeeFIM consists of 6 parts and has a total of 18 items: self-care, sphincter control, mobility, locomotion, communication, and social communication. Scoring is done according to whether the individual received help, did the function on time, or needed an assistive device when performing the function in each item in each section. The score for each item is between 1 (fully dependent) and 7 (fully independent), and the lowest score is 18 and the highest score is 126 (15-17).

The Child Health Questionnaire-Parent Form

The Child Health Questionnaire-Parent Form (CHQ-PF50) is a frequently used clinical scale for assessing health-related quality of life in individuals with CP, allowing the assessment through their parents. The reliability and validity of the Turkish version of the scale was established by Ozdogan et al. (18). The scale consists of a total of 50 items in 14 subsections, namely, physical functioning, role/social limitations-physical, general health perceptions, bodily pain/discomfort, family activities, role/social limitations-emotional/behavioral (considered 2 domains), parental impact-time, parental impact-emotional, self-esteem, mental health, behavior, and family cohesion. It also includes a section on change in health, which compares health change in a child with CP compared to the previous year. The maximum score in each section is 100. Even though the CHQ-PF50 is a scale that evaluates the quality of life of individuals with CP in general, it is not possible to evaluate the quality of life in individuals with CP in separate from their families, especially when they are young. In this study, parental impact-emotional, parental impact-time, family activities, and family cohesion subsections were evaluated and used. These subsections, which inquired about information regarding family lives that the parents provided, were scored separately and included in the evaluation.

The relationship between the GMFCS, the WeeFIM, the number of siblings, and the family-related sections of the CHQ-PF50, namely, parental impact-emotional, parental impact-time, family activities, and family cohesion, was investigated.

Statistical Analysis

Statistical analysis of the study was performed using the Statistical Package for Social Sciences (SPSS) Version 21.0 (SPSS inc., Chicago, IL, USA). The suitability of the variables to normal distribution was examined by visual (histogram and probability graphs) and analytical methods (Kolmogorov-Smirnov/Shapiro-Wilk tests). Continuous variables are given as mean ± standard deviation, and categorical variables are given as numbers and percentages. While investigating the associations between non-normally distributed and ordinal variables, the correlations coefficients and their significance were calculated using the Spearman test. Spearman correlation was identified as follows: ≥0.80, strong; 0.70 to 0.40, moderate; <0.40, weak (19). Kruskal-Wallis variance analysis was used to compare independent group differences when parametric test assumptions were not met. A p-value of <0.05 was considered statistically significant in all analyses.

Results

Two hundred and sixteen children with CP were included in the study. The mean age of the subjects was 9.56±5.75 years (minimum: 4, maximum: 18). Eighty-nine of the subjects were female (41.2%) and one hundred twenty-seven were male (58.8%). According to the GMFCS, 6.9% of the children were in level 1, 17.1% were in level 2, 17.1% were in level 3, 26.4% were in level 4, and 32.4% were in level 5. It was found that 26.4% had unilateral spastic CP, 54.6% had bilateral spastic CP, 10.7% had dyskinetic CP, and 8.3% had ataxic CP (Table 1). The demographic information about the average age of the mother, father, and the sibling in the family are given in Table 1.

Relationships between the WeeFIM and the CHQ-PF50 were examined in children with CP, and a positive weak correlation was observed between the WeeFIM and parental impact-emotional (which is about the emotional effect of the physical and mental well-being of the children with CP and their learning skills on parents) (p=0.02, r=0.16), parental impact-time (which is about the time-related effect on parents) (p=0.001, r=0.21), Family activities (which is about the effects on daily activities, conversations, and tasks-planned to accomplish together as a family) (p=0.02, r=0.15), and Family cohesion (which is about the family's ability to live with each other) (p=0.01, r=0.17). It was observed that the family life in general was also affected positively by the increase in the independence of the children with CP in daily living activities (Table 2).

When the relationship between WeeFIM and CHQ-PF50 values in child and adolescent participants was examined separately, a weak level of correlation was observed between the independence levels in daily living activities and parental impact-time (p=0.004, r=0.26), family activities (p=0.003, r=0.26), and family cohesion (p=0.003, r=0.27), and in the adolescent group, only a weak degree of correlation was found between WeeFIM and parental impact-emotional (p=0.015, r=0.25) (Table 2).

Relationships between GMFCS and the CHQ-PF50 were examined in children with CP, and a negative weak correlation was observed between the GMFCS and parental impact-time (p=0.011, r=-0.24) (Table 2).

It was concluded that there was a weak positive relationship between the number of siblings and parental impact-emotional (p=0.03, r=0.14), parental impact-time (p=0.02, r=0.15), and family activities (p=0.001, r=0.22) (Table 2).

CHQ-PF50 values were similar in different types of cerebral palsy (p>0.05) (Table 3).

Discussion

As a result of the present study investigating the effects of independence level of children with CP in daily living activities on family life, it was found that family life was positively affected as the independence levels of the children with CP increased in daily living activities, and thus, our hypothesis was confirmed. It was concluded that the existence of a healthy sibling in the family was positively reflected in the family life. In addition, it was determined in this study that CP type

Table 1. Demographic characteristics of the children and their families

Demographic characteristics	Mean ± SD	
Age (year)	9.56±5.75	-
Mother's age (year)	37.41±8.5	-
Father's age (year)	39.76±7.01	-
	Number (n)	Percentage (%)
Sex		
Female	89	41.2
Male	127	58.8
GMFCS		
Level 1	15	6.9
Level 2	37	17.1
Level 3	37	17.1
Level 4	57	26.4
Level 5	70	32.4
Types of CP		
Unilateral spastic	57	26.4
Bilateral spastic	118	54.6
Dyskinetic	23	10.7
Ataxic	18	8.3
The number of children in the family		
One	39	18.1
Two or more	177	81.9
Participants		
Children (4-9 years old)	121	56
Adolescents (10-18 years old)	95	44

SD: Standard deviation, GMFCS: Gross motor function classification system, CP: Cerebral palsy did not have an effect on family life, but families had difficulty in time management as the functional levels of children worsened.

Many problems occur together in children with CP, and they need lifelong care and treatment. Caregivers for individuals with CP are usually their families. The existence of a disabled individual in the family and their dependence in their daily living activities adversely affect their families physically and psychosocially (3,20). In a study conducted by Ones et al. (9), it was reported that the quality of life and depression levels of the mothers of children with CP were worse compared to those of the mothers of healthy children. Dehghan et al. (21) conducted a study in 424 mothers of children with CP and reported that their quality of life was negatively affected in relation to the child's motor functions and the type of CP. Lin (22) reported that although parents' approaches seem to be different from each other, they are essentially complementary. They basically need positive social relations, they want the independence of their disabled children, as well as a decrease in the anxiety level in the family. In a study, it was concluded that as children's independence levels in daily life increased, social relations of the mothers were affected positively (23). Eker and Tüzün (24) reported that the families of children with CP had a worse quality of life than that of the families of the children with minor health problems. It was seen in the present study that family life was affected in relation to the daily living activities of the children. It was seen that the children's independence in activities, such as eating, dressing, bathing, mobility, and social communication, contributed positively to the family in terms of emotion and time. It can be said that it is easier to participate in activities planned together in the family and increasing cohesion, which has a positive effect on life. In our study, unlike the literature, the participants were divided into two groups as children and adolescents, and the effects of the independence levels of individuals in daily living activities on

Table 2. The relationship between the WeeFIM, GMFCS, the number of siblings, and the selected subdomains of the CHQ-PF50 in children with CP

		Parental impact-emotional	Parental impact-time	Family activities	Family cohesion
WeeFIM (n=216)	**r**	**0.16**	**0.21**	**0.15**	**0.17**
	p	**0.02**	**0.001**	**0.02**	**0.01**
WeeFIM-Child (n=121)	**r**	0.09	**0.26**	**0.26**	**0.27**
	p	0.32	**0.004**	**0.003**	**0.003**
WeeFIM-Adolescents (n=95)	**r**	**0.25**	0.2	0.06	0.06
	p	**0.015**	0.06	0.56	0.58
GMFCS (n=216)	**r**	-0.16	**-0.24**	-0.13	-0.09
	p	0.08	**0.011**	0.14	0.32
Number of siblings (n=216)	**r**	**0.14**	**0.15**	**0.22**	-0.019
	p	**0.03**	**0.02**	**0.001**	0.78

CP: Cerebral palsy, Spearman correlation analysis

Table 3. Comparison of the selected subdomains of the CHQ-PF50 values in different SP types

		Parental impact-emotional (mean ± SD)	Parental impact-time (mean ± SD)	Family effects (mean ± SD)	Family cohesion (mean ± SD)
Type of CP	Unilateral spastic CP	46.81±26.19	50.37±26.39	57.87±26.6	56.93±24.88
	Bilateral spastic CP	44.38±29.17	46.06±33.37	59.77±28.3	60.19±25
	Dyskinetic CP	52.87±30.93	52.02±28.66	55.01±23.1	59.78±25.6
	Ataxic CP	48.95±26.12	43.70±36.16	57.2±28.61	49.72±30.65
	p	0.65	0.69	0.82	0.53

CP: Cerebral palsy, SD: Standard deviation, Kruskal-Wallis variance analysis family life were investigated in these groups. It was concluded that while independence levels in young children with CP affect family time management, family activities, and family harmony, the level of independence in older adolescents with CP is related to the emotional state of the family. This result shows us that families of the children with CP are able to use time correctly and manage family activities and harmony within the family better in time; however, it was observed that as the independence level of the children of families with adolescents deteriorates, they are affected negatively, albeit at a low level, in an emotional sense. This result shows us that families of the children with CP are able to use time correctly and manage family activities and harmony within the family better in time; however, it was observed that as the independence level of the children of families with adolescents deteriorates, they are affected negatively, albeit at a low level, in an emotional sense. It is also thought that one of the factors affecting this situation may be the adolescence period. It is thought that adolescents with CP experience mood changes and the main reflection of these within the family may be emotional rather than other factors.

Çankaya and Günel (25) reported that the motor levels of children with CP affected families in many ways, and families of children with CP who were severely affected were under more burden and stress. Gemiköz et al. (23) concluded that the motor function levels of children with CP were not related to mothers' quality of life. Erdoğanoğlu and Günel (26) reported that the quality of life of mothers and fathers with severely affected children was worse than that of the families with mildly affected children. Yığman et al. (27) reported that as the motor and communication skills of children with CP decrease, the burden of caregivers increases and there is variability in the emotional expression processes of the family. In our study, it was concluded that as the motor function levels of children with CP deteriorated, families were negatively affected only by time management. Families of the children with CP are responsible for the care of their children and also, they need to continue their treatment at home. At the same time, they have to regularly take their children to doctor's checkups and special training centers for treatment. Therefore, they have to spend most of their time with their children. As the level of influence of the children worsens, the time they need to allocate to them increases, so families may have problems with time management.

Sibling relationship is a unique feeling that continues throughout life based on a strong physical and emotional bond. Studies have emphasized that when one of the siblings has a lifetime disability, the support provided by the other sibling/siblings is more than that in normal relationships (28). Because the disabled sibling needs emotional or physical support, the relationship can change in order of magnitude. Many siblings, including younger children, can take on the role of caregiver. Although some researchers argue the opposite, many studies have emphasized that the relationships of individuals with their disabled siblings are satisfactory, strong, and positive (29). In the present study, we examined the effect of the number of siblings on the family life in children with CP. We observed that the presence of siblings supporting the disabled child and their parents contributed positively to the family life, which increases in parallel with the number of children in the family. Although the increasing number of individuals in the household can be considered as a limiting factor for parents in terms of time management, it was seen that this was not the case according to the results of our study. We observed that the healthy sibling had a positive effect on the family life by supporting the care of the disabled sibling and contributing to the development of functional independence of the children with CP. The presence of a physically healthy individual, who is close in age, apart from the parents who provide primary care, is a condition that increases the motivation of children with disabilities. Motivation is a key to the development of motor functions. In addition, individuals learn by imitation. Mirror neurons are of great importance in the realization of motor activity, and mirror neurons are activated even by observing an activity. It is thought that performing motor activities in a wide repertoire of individuals with normal motor development in the home has positive effects on the disabled child (30,31).

This study presented that, as the independence level of children with CP decreased, the difficulties experienced by families increased and their quality of life deteriorated. The effects of the responsibilities and emotions of the families of children with CP (towards themselves, each other, and the other members of the family) on family life should not be overlooked.

Parents who have difficulty in dealing with complex problems as well as with time management and children with CP who are suffering insufficiency in self-care and dependent on others need to be supported in many areas. To this end, investigating the reasons causing difficulties for families and evaluating their family lives can be a guide in reaching a solution.

Study Limitations

In our study, it was determined that the level of independence in daily living activities of children with CP and the presence of siblings in the family may be associated with family life at a low level. It should not be forgotten that there are many factors that affect family life in children with CP, such as education level, socioeconomic factors, the environment in which the family lives, other family members, and the circle of friends. The fact that these factors were not examined was a limitation of our study. Another limitation of our study was that this study was carried out in a single city, in the city center, and in families of similar nuclear family structures. Also, the mental status of the children was not evaluated, which was another limitation of the study. More effective results can be achieved by evaluating families from different socio-cultural regions of the country.

Conclusion

As a result of our study, it was concluded that family life was affected positively in general with the increase in independence levels of the children with CP in daily living activities as well as with the increase in the number of siblings, and it was positively reflected in emotional sense, time management, family activities, and family cohesion. In addition, this study revealed that the families of severely affected children have difficulties in time management. It was also identified that the level of independence in adolescent children with cerebral palsy, unlike younger children, is related to emotional impact in family life. The evaluation of the lives of the families, who are part of the rehabilitation team, is very important for families to take care of their children more effectively. It is thought that family-centered interventions that will increase the level of independence by considering children with CP from a holistic perspective can have positive effects on family life. In addition, it should be emphasized once again that it is important to consciously support families with severely affected children in time management and in overcoming adolescence issues in adolescent patients with CP.

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Ethics

Ethics Committee Approval: The ethics committee permission was obtained from the Ethics Committee of Gazi University on 14.05.2019 (approval number: #91610558-604.01.02).

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